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Cancer Treatment Helpline: a retrospective study of the NHS Tayside experience

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ABSTRACT

Background Treatment-related toxicity and delays in the management of this toxicity can impact the outcomes of patient with cancer. In Scotland, a national cancer helpline was established to provide triage assessment for patients receiving systemic anticancer therapy (SACT) in an attempt to minimise delays in toxicity management. In this article, we describe the use and impact of the helpline in our region over the last 5 years.

Methods Patients who contacted the NHS Tayside cancer helpline between 1 January 2016 and 31 December 2020 were retrospectively identified. Patient demographics as well as the reason and outcome of each call was recorded. A descriptive analysis was performed.

Results 6562 individual patients received SACT and 8385 calls were recorded during the time period. Median age of callers was 63 years (range 17–98) and 59.2% were women. Use of the helpline increased by 83.6% between 2016 and 2020, driven by an increase in in-hours calls. 41% of calls required review by a healthcare professional only, 24% required review and admission and the remaining 35% telephone advice only. The majority of cases (85%) were either assessed or advised solely by oncology. The proportional use of general practitioner services has decreased.

Conclusions The helpline provides a way for patients to report symptoms directly to their clinical team and receive appropriate specialist advice at an early stage. We demonstrate that most of these calls can be managed solely by our oncology team. This system can reduce pressure on other parts of the local health system.

INTRODUCTION

The global cancer burden is increasing annually. By 2030 it is predicted that there will be 4 million people in the United Kingdom (UK) living with cancer.¹ Despite advances in cancer management, patients still experience a range of short and long-term treatment-related side effects, which can result in significant morbidity and mortality.²

In the UK, patients with cancer presenting to their local hospital as an emergency were historically admitted under general medical or internal medicine teams. This was despite a lack of experience in managing cancer treatment-related toxicity and the limited presence of specialist oncology support in

smaller hospitals. In 2008, the National Confidential Enquiry into Patient Outcome and Death (NCEPOD)³ found deficiencies in the management of patients with cancer admitted to hospital as an emergency; 49% of patients were deemed to have had less than optimal care and 27% of deaths were adjudged to have been hastened or caused by systemic anticancer therapy (SACT). The report highlighted contributing factors relating to both the communication and organisation of emergency care.

As a result, the National Chemotherapy Advisory Group was established.⁴ They proposed that each hospital with an emergency department (ED) should have an acute oncology service (AOS) with the goal of approaching emergency cancer presentations in a more systematic way. The primary purpose of an AOS is to coordinate the management of patients who fall into one of three categories: those with cancer-related symptoms, those with cancer treatment toxicity, those requiring investigation and diagnosis of a new undiagnosed cancer.

In Scotland, in response to the NCEPOD report, a Short Life Working Group was established and developed a dedicated 24-hour Cancer Treatment Helpline (CTH) which made use of the pre-existing NHS24 helpline. At the time, it was the only validated service in the UK which utilised competently trained non-clinical staff to triage patients. The availability of the triage service provided a way for patients to directly report treatment-related toxicity and receive specialist input in a timely manner. This is important as delays in managing symptoms can impact patient outcomes—the best example of this is neutropenic sepsis.⁵

NHS Tayside is in the North-East of Scotland and serves a population of over 400 000 people. The chemotherapy service and oncology department work across two main hospital sites; Ninewells Hospital in Dundee and Perth Royal Infirmary. Due to the



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geography of the region, patients can travel up to an hour for treatment. In January 2013, NHS Tayside established a triage service with the goal to enhance patient safety and outcomes for those receiving SACT who developed symptoms related to their treatment. This service was based in Dundee and was designed to provide triage assessment for all patients with cancer in the region through an initial telephone consultation, with the goal of streamlining the patient pathway.

In October 2015, NHS Tayside adopted the CTH, a national cancer helpline established in conjunction with NHS Scotland and NHS24. In Tayside, unwell patients contacting the helpline in hours (weekdays between 08:00 and 17:00), are directed to their local oncology service, where they are triaged by a trained oncology nurse. Those presenting out of hours (OOH) are initially diverted to the CTH for triage. During the initial OOH CTH telephone triage assessment, a trained non-clinical handler triages callers using a series of questions from the United Kingdom Oncology Nursing Society (UKONS) toolkit.⁶ This toolkit uses a structured method to communicate critical information required to assess and appropriate action.⁷ Symptoms are systematically scored according to colour; green (no or mild symptoms), amber (moderate symptoms) or red (severe symptoms).

Based on the triage outcome, the patient can either be managed over the phone, reviewed OOH in the patient's local oncology department, seen by a general practitioner (GP) in the community or referred to their local accident and emergency department (ED). Each OOH call is communicated to the local oncology team the following day regardless of the outcome. [Figure 1](#) provides an example of this patient pathway.

In this article, we provide a descriptive analysis of the use of the CTH in NHS Tayside over a 5-year period (1 January 2016–31 December 2020) and discuss the impact it has had on the wider NHS in our region.

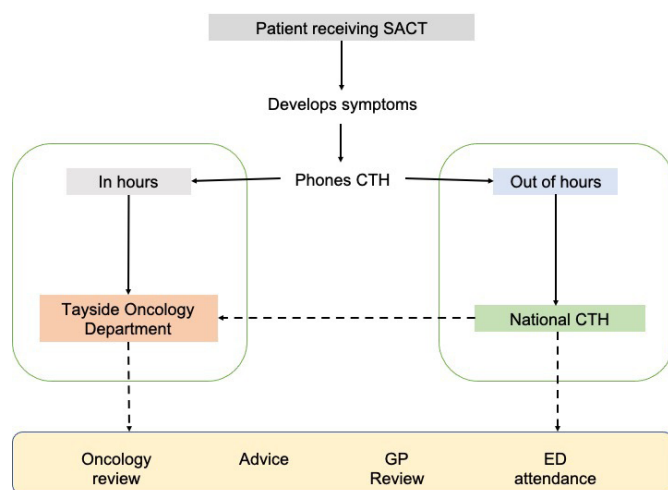


Figure 1 The CTH patient pathway in hours and out of hours in NHS Tayside. CTH, Cancer Treatment Helpline; ED, emergency department; GP, general practitioner; SACT, systemic anticancer therapy.

METHODS

Patients

Patients who contacted the NHS Tayside CTH between 1 January 2016 and 31 December 2020 were retrospectively identified from existing paper call logs.

The date, time and outcome of each call were recorded along with the primary reason for the call. The reason for the call and the symptoms experienced by the patient were graded according to the UKONS triage tool.⁶ The time of the call was recorded as in hours (08:00–17:00 on Monday to Friday) or OOH (17:00–08:00 on Monday–Friday and all-day Saturday and Sunday). The outcome of the call was recorded as advice given, oncology review, NHS24 contact, paramedic/ED attendance or GP review. If the outcome resulted in a hospital admission, this was also recorded.

Electronic records were reviewed to complete data collection including confirmation of patient age, type of malignancy and SACT being received at the time of call. Treatment was classified as either chemotherapy, immunotherapy, tyrosine kinase inhibitors, combination therapy or other therapy. Combination therapy included combinations of same or different class drugs. Other therapy included radiotherapy (alone or in combination with chemotherapy), anti-oestrogen (exemestane, fulvestrant), CDK4/6 inhibitors (ribociclib, abemaciclib, palbociclib), PARP inhibitors (olaparib, niraparib), bisphosphonates (pamidronate, zoledronic acid), targeted therapy (trastuzumab, pertuzumab, cetuximab, trastuzumab emtansine, bevacizumab, panitumumab, olaratumab), antiandrogens (enzalutamide, abiraterone), mTOR inhibitor (everolimus), somatostatin analogues (lanreotide) and dexamethasone. Accurate treatment data were unavailable for 2016 as it was not recorded on the paper logs at that stage.

All patient data were anonymised and collected in a password protected database on secure NHS computers.

Statistics

A descriptive analysis of patient demographics, the number of calls and the outcomes of each call was performed to assess differences between 2016 and 2020. Comparison of age of caller was compared between years using a two-sided unpaired t-test using Microsoft Excel.

Patient and public involvement

Patients were not involved in this retrospective study.

RESULTS

The total number of calls to the CTH between 1 January 2016 and 31 December 2020 was 8385. The median age of callers was 63 (range 17–98) and 59.2% were women. From the data, we observed that 5466 (65.2%) of calls required the patient to be reviewed in person, while 2919 (34.8%) received advice only. During the same time period 6562 individual patients received SACT in Tayside ([table 1](#)).

Table 1 Total number of calls to the NHS Tayside Cancer Treatment Helpline between 2016 and 2020

| Year | 2016 | 2017 | 2018 | 2019 | 2020 |
|--------------------------------------|------|-------|-------|-------|------|
| Number of patients who received SACT | 1212 | 1254 | 1285 | 1412 | 1399 |
| Total number of calls | 1137 | 1433 | 1773 | 1967 | 2087 |
| Year on year increase (%) | – | +26.0 | +23.7 | +10.9 | +6.1 |

Percentage year on year increase indicates the change from the previous year.
SACT, systemic anticancer therapy.

Use of CTH

The total number of calls to the CTH has gradually increased year on year, with an increase of 83.6% since 2016 (table 1). Over the same time period, the number of patients being treated has increased by 15.4%. The number of in-hours calls to the CTH has also increased year on year from 530 in 2016 to 1421 in 2020, which corresponds to an increase in the proportion of calls. In the same time period, the number of OOH calls has remained relatively constant (table 2).

Analysing the data according to the day of the week, the highest number of calls were observed on a Monday, with a total of 1903 calls (20%) being logged. There was an annual increase in calls on each weekday while number of calls on weekends remained similar. The majority of calls during the day were received in the morning with the greatest number of Monday morning.

Use of CTH according the age

The median age of patients using the CTH was 63 years (range 17–98). There was an increase in the number of calls across all age groups from 2016 to 2020. There was no significant difference in median age of patient across the years (table 3).

Impact of tumour group and regime

In keeping with the incidence of the common cancers, the use of the CTH was greatest in patients with breast, lung and colorectal cancer (table 4). Most tumour groups had an increase in call number—the exception was prostate cancer.

The greatest number of patients were on a form of combination treatment at the time of their call. Between 2017 and 2020, the largest increase in use of the CTH was seen for immunotherapy and other treatments; 215% and 225% increase, respectively. Calls related to

chemotherapy, tyrosine kinase inhibitor and combination therapy increased by 21%, 41% and 26%, respectively.

Call outcome

Of the 8385 patients that have used the CTH between 2016 and 2020—41% required review by a healthcare professional only, 24% required review and admission and the remaining 35% were given telephone advice only (table 5). The majority of cases (85%) were either assessed or advised solely by oncology. Of note, the proportional use of GP services has decreased, while the number of patients being reviewed by oncology has increased by an equal proportion. It is important to note the likely impact of the COVID-19 pandemic on the 2020 data, with an increase in advice and a fall in clinical review.

When assessed according to time of call, a difference in both type of outcome (table 6) and the admission rate is observed (table 7). Calls in hours had a higher review and discharge rate (30.1% vs 20.8%) and a lower admission rate (18.0% vs 33.6%) compared with OOH calls. We also observe that the admission rate in hours has reduced over time, while the OOH rate has remained stable (table 7).

DISCUSSION

The NCEPOD report in 2008 suggested that failure to provide a robust 24-hour oncology advice service resulted in compromised safety for patients with cancer.³ In response, Scotland established a 24-hour CTH with the aim of providing a direct route of contact for patients to report their treatment-related toxicity directly to their clinical team. In this article, we describe the use of the CTH in our oncology service in NHS Tayside, as well as the impact it has had on service provision in the wider local health service.

Our data demonstrate that the number of calls received by the CTH has increased by 83.6% over the last 5 years. This is in keeping with rising incidence of cancer⁸ as well

Table 2 Number of in-hours and out-of-hours calls from 2016 to 2020

| Year | Total calls | In hours | Out of hours |
|------|-------------|--------------|--------------|
| 2016 | 1137 | 530 (46.6%) | 607 (53.4%) |
| 2017 | 1433 | 777 (54.2%) | 656 (45.8%) |
| 2018 | 1773 | 1085 (61.2%) | 688 (38.8%) |
| 2019 | 1963 | 1235 (62.9%) | 728 (37.1%) |
| 2020 | 2053 | 1421 (69.2%) | 632 (30.9%) |

Percentage expressed as proportion of calls according to individual year.

Table 3 Median age (range) of patients who called the Cancer Treatment Helpline from 2016 to 2020

| Year | Median (years) |
|------|----------------|
| 2016 | 63 (23–85) |
| 2017 | 64 (17–90) |
| 2018 | 63 (21–89) |
| 2019 | 62 (18–98) |
| 2020 | 64 (18–95) |

Table 4 Breakdown of Cancer Treatment Helpline use by tumour group from 2017 to 2020

| Tumour group | 2017 | 2018 | 2019 | 2020 | Total | % change |
|--------------|-----------|-----------|-----------|-----------|------------|----------|
| Breast | 295 (21%) | 387 (22%) | 477 (24%) | 465 (22%) | 1624 (22%) | 58 |
| Lung | 305 (21%) | 405 (23%) | 413 (21%) | 408 (20%) | 1531 (21%) | 38 |
| Lower GI | 167 (12%) | 240 (14%) | 264 (13%) | 276 (13%) | 947 (13%) | 65 |
| Gynae | 191 (13%) | 183 (10%) | 220 (11%) | 203 (10%) | 797 (11%) | 6 |
| Upper GI | 173 (12%) | 155 (9%) | 170 (9%) | 263 (13%) | 761 (10%) | 52 |
| Prostate | 105 (7%) | 101 (6%) | 105 (5%) | 80 (4%) | 391 (5%) | -24 |

Only tumour groups with more than 100 calls in 2017 are shown. The percentage (%) change from 2017 to 2020 is recorded.
GI, gastrointestinal.

as the availability of newer treatments such as immune checkpoint inhibitors, which provide the option of more lines of therapy for our patients. There was no significant change in the median age of patients we observed calling the CTH. Interestingly, while the in-hours calls increased (almost trebling), the out-of-hours calls did not, possibly reflecting a hesitancy from patients to phone outside traditional working hours. This is supported by the sharp increase in calls on a Monday, and in particular Monday morning, suggesting that patients were willing to wait to call until after the weekend.

Of the calls to the CTH, 35% were able to receive telephone advice only. 85% were dealt with exclusively by the local oncology team either with telephone advice or in person review. This demonstrates the impact the CTH has had on appropriately directing patients and receiving early specialist care. This has also had a positive impact on other parts of the health service. As the CTH has developed and the team has increased in size and experience, the proportion of patients requiring review by their GP has fallen from 15% in 2016 to 11% in 2020, while the number receiving oncology review has increased by the same proportion. This demonstrates a shift in care

model. This is also reflected in the triage classification which has demonstrated a reduction in acuity of calls and a move towards a greater proportion of green and single amber calls (data not included)—suggesting patients are phoning at an earlier stage of their toxicity burden. The reduction in the in hours admission rate over time adds weight to this theory and may also suggest an increasing confidence in the oncology clinical team in management of toxicity.

It is important to note that there was a change in triage outcome in 2020, which likely represents the impact of the COVID-19 pandemic on SACT delivery in Scotland.⁹ During this year, a greater proportion of patients received advice only which may represent not only a propensity to avoid patients coming to a high-risk clinical area but also a tendency for clinicians at the beginning of the pandemic to dose de-escalate, use increased supportive measures and dose delay. All of these measures would reduce incidence and severity of toxicity.

Most tumour groups have observed an increase in call burden—reflecting the increase in number of patients with cancer and improved patient survival as well as the increased number of treatment options available. The

Table 5 Outcome of calls to the Cancer Treatment Helpline between 2015 and 2020

| Year | Advice only (%) | GP/NHS24 (%) | Oncology review (%) | ED review (%) | Admission (%) |
|-------|-----------------|--------------|---------------------|---------------|---------------|
| 2016 | 30 | 15 | 26 | 3 | 27 |
| 2017 | 32 | 12 | 25 | 2 | 29 |
| 2018 | 31 | 10 | 30 | 2 | 27 |
| 2019 | 31 | 11 | 31 | 4 | 22 |
| 2020* | 46 | 11 | 20 | 4 | 19 |

Values expressed as percentage of total calls to nearest whole number.

*COVID-19 pandemic.

ED, emergency department; GP, general practitioner.

Table 6 Outcome of Cancer Treatment Helpline call according to time of call; in hours and out of hours

| | Advice only | GP/NHS24 | Oncology review and discharge | ED review | Admission |
|--------------|--------------|-------------|-------------------------------|------------|--------------|
| In hours | 1877 (37.0%) | 700 (13.8%) | 1523 (30.1%) | 57 (1.1%) | 911 (18.0%) |
| Out of hours | 1042 (31.4%) | 277 (8.4%) | 691 (20.8%) | 192 (5.8%) | 1115 (33.6%) |

Figures expressed as total number of calls and percentage.

ED, emergency department; GP, general practitioner.

Table 7 Admission rate per 100 calls to the Cancer Treatment Helpline according to time of call; in hours or out of hours

| Year | Admission rate/100 calls | |
|------|--------------------------|--------------|
| | In hours | Out of hours |
| 2016 | 20.2 | 32.3 |
| 2017 | 22.3 | 37.3 |
| 2018 | 20.8 | 37.8 |
| 2019 | 15.8 | 31.5 |
| 2020 | 14.8 | 30.3 |

exception is prostate cancer, which has seen a reduction. This is likely a result of the introduction of the oral agents abiraterone and enzalutamide, which in general are better tolerated in comparison to chemotherapy and require regular clinical review in the clinic setting.

Likewise, all treatment types have noted an increase in calls. This increase is particularly marked for immune-checkpoint inhibitors which over the past 5 years have been licenced for use in several tumour groups both in the adjuvant and palliative setting.

The strengths of this report are that we have generated a large amount of data over a period of time from the same oncology unit. We have used a standardised reporting form which has enabled consistency in data recording and minimised missing data. Despite this, our report has several limitations. The first is that our centre is the smallest in Scotland and as such our patient numbers are lower than other centres. In addition, our model of care differs from the other Scottish cancer centres. This makes our findings challenging to extrapolate to larger centres both within Scotland and across the UK. We also must recognise that although standardised reporting forms were used, the recording of the patient symptoms using the UKONS tool is open to interuser variability and we did note some data were missing. Finally, there is a lack of granularity regarding burden of disease must also be acknowledged, as this could influence call burden and outcomes.

Overall, we feel our data support the use of a CTH within the NHS pathway for patients with cancer. It is accessible to patients of all ages and facilitates direct contact with the treating team. The end result is a more personalised and streamlined approach to toxicity management. Within our unit, use of the service continues to increase as delivery of SACT increases. In response, we are expanding our acute oncology team. This will have two main impacts; it will provide support for general medical teams caring for patients with cancer and it will enable expansion of 'in hours' times to cover from 08:00 to 20:00 7 days per week. This may result in an increase in calls at weekends and subsequent fall in calls on Monday mornings. Our data also suggest that admission rate may fall with an expansion of 'in hours' service. The decrease in proportional use of GP services and the high level (85%)

of calls that were able to be managed solely by oncology services suggests this is a sustainable and beneficial model of care. Importantly, the fall in admission rates also suggests that patient outcomes are improving.

Although patient pathways in individual cancer centres differ across the UK, the principles detailed in this report are applicable in general—providing a direct route of contact for patients to receive advice and an appropriate management plan for their toxicity. This may involve various outcomes as shown in figure 1. Published data on the impact of such a model in other larger centres are currently lacking.

In summary, we provide an overview of the CTH in our region. We believe this is the first report of its kind. We have shown that use of the CTH has increased over the last 5 years and the ability to direct patients to specialist care early has removed pressure on other parts of the health system.

CONCLUSION

Early reporting and management of treatment-related toxicity improves patient's outcomes and quality of life. The CTH provides a way for patients to report their symptoms directly to their clinical team and receive appropriate specialist advice at an early stage. We have demonstrated that most of these calls can be managed solely by the oncology team and that this can remove the pressure on some of the other parts of the local health system. The CTH fits within our local AOS service.

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Contributors IT and SG analysed the data and drafted manuscript. They are joint first authors. MT oversaw data collection and edited the manuscript. RDP edited the manuscript. MB designed the project, analysed the data and wrote the manuscript. All authors approved the final manuscript.

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Patient consent for publication Not required.

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Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Deidentified data can be obtained on request from the corresponding author.

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